



# Building FASD State Systems Meeting Proceedings

San Antonio, Texas • June 20-22, 2005



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Substance Abuse and Mental Health Services Administration  
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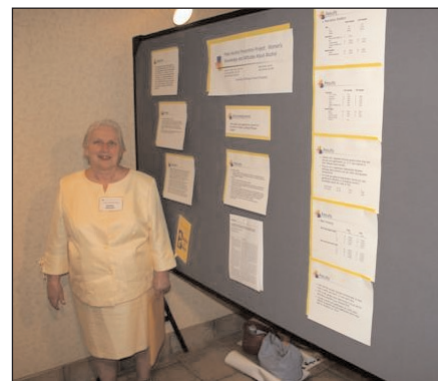
SAMHSA  
Fetal Alcohol Spectrum Disorders  
Center for Excellence

## Introduction

The Substance Abuse and Mental Health Services Administration (SAMHSA) Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence convened the third “Building FASD State Systems” (BFSS) meeting in San Antonio, Texas, on June 20 through 22, 2005. The BFSS meetings are designed to facilitate the creation and enhancement of comprehensive systems of care for FASD. The BFSS meeting is part of the SAMHSA FASD Center’s response to its legislative mandate to provide technical assistance (TA) to communities developing systems of care.

### Monday, June 20, 2005

On the evening of June 20, attendees participated in an opening reception and poster session during which about 25 groups shared posters or materials about the FASD activities in their State. Attendees learned about effective strategies and networked with one another. Afterward, they had the opportunity to view the video *Recovering Hope: Mothers Speak Out About Fetal Alcohol Spectrum Disorders*.



### Tuesday, June 21, 2005—Plenary Sessions

#### Welcome and Introduction

**Ammie Akyere Bonsu, MPH**, Project Officer, SAMHSA  
FASD Center for Excellence

On behalf of Mr. Charles Curie, SAMHSA Administrator, and Ms. Beverly Watts Davis, Director of the Center for Substance Abuse Prevention (CSAP), Ms. Bonsu welcomed participants to the third BFSS meeting. She introduced herself and thanked the BFSS Planning Committee for their efforts in organizing this event.



The BFSS meeting is a direct response to two of the Center’s congressional mandates: to identify comprehensive systems of care and to provide TA to communities with and without these comprehensive systems. This meeting presents an opportunity to (1) continue to dialog across Federal agencies, States, and local constituency groups and (2) forge partnerships to focus attention on developing more prevention and treatment efforts in communities disproportionately affected by FASD. One of the greatest achievements

resulting from the BFSS meetings to date is the establishment of the National Association of FASD State Coordinators (NAFSC), in which 13 State Coordinators participate.



To adequately address FASD, increased awareness and prevention and intervention services are needed, as is an infusion of FASD into the agendas of State and tribal government agencies. SAMHSA is pleased with the accomplishments of the States in these areas and appreciates the participants' willingness to attend this meeting to network and share ideas. Ms. Bonsu remarked on the many service systems represented at this meeting and recognized the Center's 35 State, local, and juvenile court contractors, some of which were in attendance.

Ms. Bonsu left participants with a simple charge: To continue to educate policymakers.

## **SAMHSA FASD Center for Excellence: Accomplishments Since May 2004 and Future Directions**

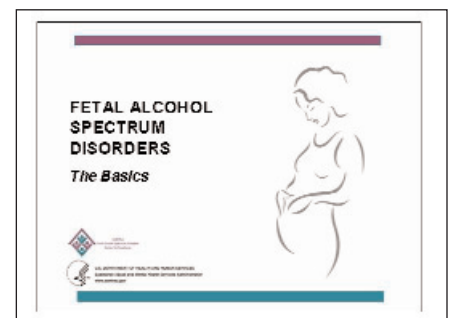
**Callie Gass, Project Director**, SAMHSA FASD Center for Excellence

In the year since the last BFSS meeting, the Center's main activities have been in three areas: establishing subcontracts, starting up the American Indian/Alaska Native Initiative, and developing materials.

In the summer and fall of 2004, the Center solicited proposals and awarded subcontracts to 20 local communities, 10 States, and 5 juvenile courts in geographically and culturally diverse areas of the United States. The subcontractors will attempt to integrate evidence-based FASD prevention or treatment activities into an existing service delivery system, document the process, and measure outcomes. They also are charged with sustaining their projects after funding ends. The subcontractors, currently in their planning year, have taught the Center several lessons about barriers to implementation. The Center also has learned that social service agencies and courts have a high level of awareness of FASD and are eager to effect change.

In the area of publications and products, the Center continued to be very active. Some of the products Ms. Gass highlighted included the following:

- "Understanding Fetal Alcohol Spectrum Disorders: Getting a Diagnosis," a popular fact sheet providing guidance to parents and others with custody of alcohol-affected children.
- Rack cards and posters created by the Partnership to Prevent Fetal Alcohol Spectrum Disorders. These are available in English and Spanish and target women at moderate risk.
- "FASD: The Basics," a set of downloadable slides in PowerPoint, HTML, and PDF formats. The Center encourages trainers and others to use all or parts of the slides as needed. The notes contain detailed information and literature sources.
- "Many Doors, No Master Key" slides, which depict the resources needed for a child, Brandan, at age 1 to 2 years and later during his elementary school years.



- “FASD Curriculum for Addiction Professionals” (under development by the Center). The Center will encourage the inclusion of questions about FASD in State certification exams for addiction professionals, and this curriculum will be used in this effort.
- “Tools for Success” curriculum for professionals in the juvenile justice system (under development by the Center and the Minnesota Organization on Fetal Alcohol Syndrome, or MOFAS).
- *Recovering Hope*, a video that follows women in treatment as they learn about FASD and get help for their children. This video, produced by Westat and an independent producer, has won several awards in the past year. Ms. Gass encouraged participants to take a copy with them.

Ms. Gass also shared information about a new effort the Center is planning, the American Indian/Alaska Native Initiative. Proposed activities include holding four BFSS-type regional meetings with tribal representatives, recasting materials to make them culturally appropriate for Native audiences, and convening training institutes. The Center also hopes to award subcontracts to support the development of women’s summits in Indian Country. The activities proposed for the initiative resulted from a tribally representative stakeholders meeting the Center convened.

The Center continues to provide training and technical assistance and manage the Information Resource Center. In addition, the Center is working with NOFAS to plan a Hope for Women in Recovery meeting and a Circle of Hope meeting scheduled for July in Raleigh, North Carolina.

## New Estimates of the Economic Impact of FASD

**Rick Harwood, Vice President, The Lewin Group**

Mr. Harwood began by explaining the purpose of his presentation: to provide cost data to help participants educate policymakers, people in their health departments, and others in their State about FASD. While attendees already were familiar with the human costs of FASD, this presentation articulated costs in dollars, a metric decisionmakers use everyday. Highlights related to costs included the following:

- FAS cost the United States \$5 billion in 2004, which translates to \$17 per capita and \$17,000 per case of FAS. This is a conservative estimate of the burden, because it does not include other disorders associated with prenatal alcohol exposure. The costs of FASD are probably much higher because:
  - The United States has up to 41,000 alcohol-affected births per year, and only 4,100 of them are cases of FAS.
  - The population of people with other fetal alcohol spectrum disorders, which is 5 to 9 times the size of the population with FAS, appears to require more services than people with FAS.
  - The estimate is conservative by design. Estimates tend to err on the conservative side.



- One FAS birth carries lifetime health costs of \$843,000, although costs can be as high as \$3.7 million. Today, these lifetime costs are equal to about \$290,000 and \$1.3 million, respectively. These figures represent the amount of money that would need to be invested now to have the lifetime costs available over time.
- FAS prevention may be considered “generally cost-effective” at costs up to \$546,000 per FAS case prevented.

In attempting to develop cost estimates for FASD, it became clear that data about incidence and the severity of problems are lacking for diagnoses other than FAS. Therefore, the cost study only includes the costs of FAS. In addition, for a number of years, research has indicated an association between FASD and mental illness and trouble with the law, but data related to these costs are limited. As a result, the costs associated with mental health services and the justice systems are conservative.

Most of the presentation focused on the “cost of illness” study, which assesses the overall burden on the economy in use and loss of resources per year. The cost of illness study takes these costs into account:

- Direct costs (the cost of goods and services), such as costs to the health, social, and justice systems. The estimate includes, for example, the costs of special education, primarily physical health, and adult care services.
- Indirect costs (the costs of foregone potential productivity) resulting from mortality, morbidity, disability, and incarceration.

Mr. Harwood detailed the process for estimating all the costs that contribute to the cost of illness and then briefly described the calculations used to estimate cost effectiveness.

The Lewin Group plans to complete calculations of State-specific cost estimates in 6 to 8 weeks.



### Questions and Comments

In response to a question about whether The Lewin Group’s State-specific cost estimates would take levels of alcohol consumption into consideration, Mr. Harwood said that estimates would use SAMHSA and Centers for Disease Control and Prevention (CDC) surveys, which include factors related to alcohol use. The Lewin Group will present the estimates with an explanation of how it established them.

A few members of the audience made suggestions for presenting the cost data:

- Present the costs of FAS in comparison to the costs of conditions with which people are more familiar.



- Estimate the financial costs assumed by families in geographic areas in which services do not exist (for example, the costs of parents not working).

Another participant reflected on some of the issues raised by this presentation:

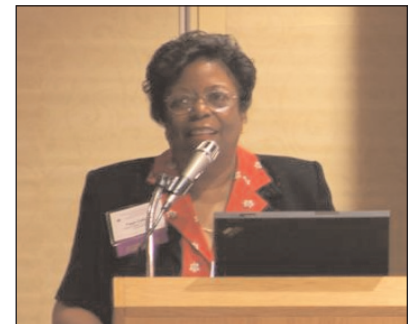
- Mr. Harwood's graph depicting the costs of FAS over a lifetime shows no costs for the few years preceding elementary school. Because early intervention services can contribute to the long-term prognosis of children with a disability, early screening, diagnosis, and intervention are needed.
- Interventions or services for the families of persons with an FASD would be more cost-effective if they also would benefit the families of other children at risk.

### Keynote Speaker's Address

**Introduction: Ammie Akyere Bonsu, MPH**, Project Officer, SAMHSA FASD Center for Excellence

**Faye Calhoun, DPA**, Deputy Director, National Institute on Alcohol Abuse and Alcoholism (NIAAA), and former Co-Chair, SAMHSA FASD Center for Excellence Steering Committee

Dr. Calhoun began her presentation by outlining the history of FASD:



- 1968—At the University of Washington, a medical resident named Christy Ulleland recognized that children with similar facial features and problems had been prenatally exposed to alcohol. She gathered the children and showed them to Kenneth Jones and David Smith, who coined the term “FAS” in 1973. Dr. Calhoun led the participants in a round of applause for Dr. Ulleland and said she would like to see Dr. Ulleland at the next BFSS meeting.
- 1973—Under the leadership of Kenneth Warren, NIAAA began conducting research to examine the effects of prenatal alcohol exposure.
- 1996—The Institute of Medicine (IOM) issued a report stating that adequately addressing FAS required interagency coordination.
- 1996—NIAAA and CDC, both of which funded research on FAS, began convening meetings and formed what would become the Interagency Coordinating Council on FAS (ICCFAS).
- 2001—Congress funded the SAMHSA FASD Center for Excellence. The Center, guided by a Steering Committee, is the centerpiece of a true partnership.
- 2004—NOFAS convened a meeting during which the term “FASD” was adopted. This new term acknowledges the spectrum of disorders associated with prenatal alcohol consumption.
- 2005—The Surgeon General issued an advisory about drinking during pregnancy. This advisory differs from the original, written in 1981 by Dr. Warren, in that it advises women who





are *considering getting pregnant* not to drink. This change aims to prevent drinking among women who are pregnant but do not know it yet.

- 2005—The Congressional Caucus on FASD formed. Participants should determine if their representatives are members. Whether or not their representatives serve on the Caucus, participants should encourage them to be involved, because representatives have to sign up for Caucuses annually. The Caucus asked ICCFAS for a report on FASD, and that report is in the clearance process.

Dr. Calhoun presented an organizational chart depicting the various agencies within the U.S. Departments of Health and Human Services, Education, and Justice that participate in ICCFAS. The U.S. Department of Agriculture may also join ICCFAS because it funds the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) and 4-H activities, both of which can be involved with prevention efforts.

In moving FASD efforts forward in their States, participants should involve all the domains represented on ICCFAS (e.g., health, education, developmental disabilities, research). Dr. Calhoun praised the important work of the States thus far, as evidenced in the posters they presented at the opening reception and poster session, and imparted some advice for improving their efforts:

- Post copies of the Surgeon General's advisory in local establishments, such as beauty salons and barber shops.
- Educate middle school and high school youth about the effects of prenatal alcohol exposure, since many of them are drinking alcohol and engaging in sexual activity.
- Identify people who are passionate about FASD and can help with advocacy.

Dr. Calhoun briefly described some of the activities in NIAAA's international FAS research. NIAAA's International Collaborative Research program funds research in six countries outside the United States and aims to (1) build an international multidisciplinary and multicultural team of scientists and clinicians, (2) develop increased capacity to address FAS in the participating countries, and (3) advance the research and scientific knowledge about FASD. Dr. Calhoun had the opportunity to visit one site in South Africa, where she asked five 9-year-old children to draw pictures of themselves. She shared their pictures, which were drawn at a capacity level of a 4-1/2- to 6-1/2-year old.

### **NOFAS and the REACH Project**

**Kelly Raiser, MPH**, Program Associate, National Organization on Fetal Alcohol Syndrome

Mr. Raiser thanked the Center for involving NOFAS in this meeting and noted that NOFAS recently celebrated its 15th anniversary. With funding from the Harry and Jeanette Weinberg Foundation, NOFAS awarded 2-year grants to four communities under the REACH project (Reducing FASD Through Education, Advocacy, Community Action, and Health Information



Dissemination), and he introduced the four groups. They conduct peer education and implement community awareness projects in various locations, such as schools, community events, and teen town hall meetings. The culmination of this project will be a guide to help communities create a peer education program. Mr. Raiser asked each of the tribes to introduce themselves, noting that representatives of the fourth grantee, Standing Rock Sioux, could not attend the meeting:

- Louise Ashkie, Program and Project Specialist, Navajo Nation, and Leeann Kee and Mikki Garnenez, peer educators. Ms. Kee conducted 5 trainings reaching 500 students and conducted media outreach on a radio station with 68,000 listeners. Ms. Garnenez conducted outreach to 525 youth at sports camps.
- Laura John, REACH Site Coordinator, Native American Rehabilitation Association of the Northwest, and Delaney Reed, Robert Spector, and Bryce Granbois, peer educators. These peer educators attend youth conferences and work with high schools in Portland, Oregon, and the various reservations nearby.
- Bettye Tate Gardner, MA, LPC, NCC, CPM, Director, Choctaw Behavioral Health, Mississippi Band of Choctaw Indians, and Ashton Thompson, Cherish McMillan, and Lakeishia Wallace, peer educators. The peer educators reached 350 people through 6 trainings, developed a fact sheet, and produced a public service announcement (PSA) that airs on a local television station that reaches 3,000 homes. They showed the PSA, which describes the goal of the peer education project, the prevalence of FAS, and the cause and characteristics of alcohol-related disorders.

### Personal Stories From Parents of Children With an FASD

**Moderator: Mercedes Alejandro**, Parent, The Arc of Greater Houston, and Member, SAMHSA FASD Center for Excellence Steering Committee

**Cheryl Plumage**, Parent, Montana

Ms. Plumage introduced herself in the Native way and as Iron Woman (in the Assiniboin language). She spoke of her son, who will be 30 years old this September. When she was pregnant with him, she said, she violated the holiest ceremony women have: the ceremony of carrying life. She drank alcohol when she was pregnant, even though she knew in her heart that she was hurting her child. When she drank, she would feel the baby stop moving, and she would say that he was sleeping, but he was really passed out from the alcohol.

One month before she gave birth, her husband was killed in a car accident. She gave birth in an Indian Health Service (IHS) hospital in Montana. When the baby was born, he did not cry until the doctor provoked him. When she held her son, she could smell alcohol. The next day, the doctors said that her baby was dehydrated and needed to go to another hospital to get intravenous fluids. Doctors took her baby and left her alone in a room. Doctors later recommended that she should improve her breast milk by drinking two to three beers per day.





Ms. Plumage was sober for 11 years before she could deal with the fact that she permanently damaged her baby. It has been devastating. When she is asked to speak about her experience, she does so because her son wants her to. If one child can be saved, he says, it is worth her telling her story. Her son's name is Many Feathers Around the Head, which means that he is a great warrior, and the family believes that he is one.

When she went home to her reservation in 1989, she was told that FAS did not exist there. Now, because of Phil May's work, a program there is conducting research on FAS.

**Mary DeJoseph, DO**, Parent, New Jersey

Dr. DeJoseph expressed thanks for the privilege of telling her story and said that many of her heroes were in the room. Dr. DeJoseph grew up in a family with alcoholism. The women in her family drank until they died of cirrhosis in their 40s. She started drinking in shame and secrecy by age 8. As a teenager, she led a double life—getting good grades and serving as editor of the school paper but keeping vodka in her locker at school.

When she was pregnant with her first child, she stopped drinking for a year but began drinking again afterward. She did not know recovery from alcoholism was possible. While she was drinking, she learned that she was in her second trimester of another pregnancy. She was suicidal everyday during this pregnancy. Even though she had lived through difficult times, including being a runaway, this was the scariest time of her life. When her son, Michael, was born, both she and Michael were in alcohol withdrawal. Shortly thereafter, she went into an alcohol-induced coma. Subsequently, she entered rehabilitation and started recovery.

Dr. DeJoseph was able to get Michael access to early intervention services, but mainstreaming was not successful. He was diagnosed at age 8 with FAS. She found the FAS Family Resource Institute to be an invaluable source of help. One day, while Dr. DeJoseph and her son were talking in the car, he came to understand that she drank alcohol when she was pregnant with him, and he asked her if it was true. She said it was, and she asked him if he could ever forgive her. He said, "I don't mind, Mommy, I still love you." Because he could forgive her, she could forgive herself.

She closed her story by explaining that forgiveness can follow the period of grief and loss and that there is hope in forgiveness.

**Moira and Jim Clark**, Parents, Wisconsin

When Ms. Clark was pregnant with her 14-year-old son, Michael, she did not receive prenatal care and she was in an abusive alcoholic relationship. When she gave birth to her son, she had bruises on her eyes. Michael weighed 2 pounds, 2 ounces. People from social services said she could not provide a safe home for her baby, but intervening social workers moved her into treatment, which changed her life. She realized that she had a disease over which she had no control, and she replaced the guilt she felt with regret.



When Michael was a baby, she had to learn how to be a mother to a child with eating and sleeping disorders. For the first 5 years of Michael's life, they did not sleep through the night.

Supportive doctors, including a good pediatrician, were instrumental in getting Michael access to services and determining which of his problems were related to alcohol exposure. Because she and Michael lived in the same place from his early childhood through high school, he has been able to see the same physical and speech therapists and other providers, which appears to have benefited him.

Mr. Clark met Michael when he was 1 year old. When Michael's home went from a one- to a two-parent household, the Clarks had to be careful not to confuse Michael with changing rules. Now, Mr. Clark is trying to teach Michael about good work ethics and responsibility. Mr. Clark teaches Michael about tools and how to work on cars.

### Questions and Comments

Audience members asked for guidance to help them prevent drinking in pregnant women. Responses included the following:

- Some women just need education about the risks of drinking during pregnancy. The stories of birth mothers can get the message across, as can brief conversations with medical health professionals.
- For other women, the idea of sobriety can be overwhelming. The most important actions to take for these women are to "be there," promote the idea of recovery, and stress that any time is a good time for a pregnant woman to stop drinking.
- Some type of controlled, safe living environment (e.g., halfway house) would benefit women who cannot stop drinking on their own.
- Identification and monitoring are needed to determine the level of intervention necessary to prevent a woman from drinking during her pregnancy.

### Implementing the CDC Guidelines: Challenges and Issues for the Future

**Moderator: Edward Riley, PhD**, Professor, San Diego State University, and Co-Chair, SAMHSA FASD Center for Excellence Steering Committee

#### Screening for FAS: What, Why, and How

**Larry Burd, PhD**, Director, North Dakota Fetal Alcohol Syndrome Center, and Member, SAMHSA FASD Center for Excellence Steering Committee

Because States often have limited capacity to perform diagnostic evaluations, an important step States can take in developing a comprehensive system for FASD is establishing a screening program. The main function of screening is to select a few



high-risk individuals from a large population of low-risk people. In other words, screening eliminates many low-risk people from those who will be referred to evaluation. With an accurate FASD screening tool, screening will increase identification of FASD among the referred group (e.g., from 1 to 20 percent) and thus help the diagnostic process operate more efficiently.

Other reasons for screening include the following:

- To establish prevalence rates
- To facilitate early identification of children who may be affected
- To link affected children to services
- To enhance prevention efforts
- To reduce mortality

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*Because screening so greatly increases efficiency, States should invest in developing a screening program.*

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Screening is brief and inexpensive and usually can be conducted by people who have little training. Despite the benefits of FASD screening, some people who have an FASD will screen negative and some people who do not have an FASD will screen positive. Screening tools are not 100 percent accurate, and they are not diagnostic or mini-diagnostic tools.

Dr. Burd has used screening effectively in various settings, including schools, Head Start settings, clinics, and residential facilities. He said he is particularly proud of a screening program on a North Dakota reservation that routinely screens every child in kindergarten.

Because screening so greatly increases the efficiency of the diagnostic process, States should invest in developing a screening program. Many screening tools are available. Dr. Burd recommended that participants examine some of the tools published in the literature and select an appropriate one for their needs. He presented a few tools he has used, including his FAS Screen form and Alcohol-Related Neurodevelopmental Disorder (ARND) Behavior Checklist. In closing, he reiterated the benefits of integrating screening into a State's system of care.

**Making the Diagnosis of FASD in Population-Based Studies: The Revised IOM Categories**  
**Phil May, PhD**, Senior Research Scientist, University of New Mexico, and Member, SAMHSA FASD Center for Excellence Steering Committee

Dr. May began his presentation by explaining the challenges involved in diagnosing children with FAS and related disorders. Diagnosis is even more challenging when evaluating children with mixed histories and mixed characteristics, children of alcohol-affected parents, and adults.

In 1996, the Institute of Medicine published criteria for the diagnosis of FAS (with or without confirmed maternal exposure), partial FAS, alcohol-related birth defects (ARBD), and ARND. IOM published the criteria with several recommendations and conclusions, among them that:



- Research was needed to test and refine the tool.
- An interagency plan was needed to estimate prevalence rates.
- It would be inappropriate to impose rigid diagnostic criteria on a syndrome with phenotypic variability.
- FAS, ARBD, and ARND will continue to be difficult to diagnose.

IOM struggled with the diagnostic category “partial FAS,” in part because the children who would fit into this diagnostic category are affected by less severe and thus less obvious symptoms than the children with FAS.

After briefly reviewing the 2004 CDC guidelines, Dr. May presented the proposed revised IOM guidelines, published in the Hoyme, et al., 2005 *Pediatrics* article distributed to participants. The writers aimed to improve the guidelines, as the IOM recommended; specifically, the revisions aim to (1) ensure that phenocopies (i.e., facial and developmental features not caused by alcohol exposure) are excluded from the diagnosis and (2) confirm maternal alcohol exposure when possible.

Dr. May detailed the components in the proposed criteria. When compared to the IOM’s five diagnostic categories and the CDC’s categories, the chief differences in the new categories are:

- I. FAS with confirmed maternal alcohol exposure—Virtually the same as the CDC’s guidelines but requires only two of three facial anomalies.
- II. FAS without confirmed maternal exposure—Same as above (I) without maternal exposure.
- III. Partial FAS with confirmed maternal alcohol exposure—In addition to confirmed maternal exposure and two facial characteristics, requires one of the following: growth retardation, CNS abnormalities, or behavioral/cognitive abnormalities.
- IV. Partial FAS without confirmed maternal alcohol exposure—Same as above (III) without maternal exposure. This is a new category.
- V. ARBD—Requires presence of one of a variety of congenital structural defects (two if they are minor).
- VI. ARND—Requires evidence of a pattern of behavioral or cognitive abnormalities. Researchers continue to develop a behavioral phenotype for this category to improve diagnosis.



Dr. May and his colleagues have applied the revised criteria in South Africa, the Northern Plains of the United States, and other areas and confirmed the tool's interrater reliability. In addition, when researchers compared the diagnoses resulting from using the original IOM and the revised IOM criteria, the revised criteria resulted in more refined diagnoses. He and his colleagues will continue to operationalize and improve the criteria.

#### **FASD 4-Digit Diagnostic Code**

**Susan Astley, PhD**, Director, FAS Diagnostic and Prevention Network, University of Washington

Rather than detailing the specific use of the FASD 4-Digit Diagnostic Code, Dr. Astley shared key differences between this diagnostic tool and others, including the CDC and IOM guidelines, with the hope that the States could use this information to select criteria to use. (Information about the 4-Digit Code can be found at <http://depts.washington.edu/fasdpn>).



The 4-Digit Code, like the CDC and IOM criteria, includes FAS (alcohol exposed), FAS (alcohol exposure unknown), and partial FAS as diagnostic categories. Rather than using ARBD and ARND as categories, the 4-Digit Code uses several other terms to describe specific deficiencies: static encephalopathy, neurobehavioral disorders, and sentinel physical findings. Dr. Astley charted the comparison of these terms at various levels of severity. She explained why the 4-Digit Code does not use the term “ARND”:

- When a child presents with cognitive/behavioral problems and alcohol exposure but no facial characteristics indicative of FAS, the physician cannot confirm that alcohol caused the cognitive/behavioral outcomes. These outcomes are not specific to prenatal alcohol exposure.
- The term “ARND” shares the same limitations as the term “FAE,” which experts recommend not be used (Aase, Jones, and Clarren, 1995).
- In the absence of knowledge that alcohol caused the child’s problems, the term “ARND” is a misdiagnosis. Misdiagnosing the child may stigmatize the mother unnecessarily.
- When alcohol exposure is known, it can be included in the diagnosis (e.g., static encephalopathy/alcohol exposed) without implying causality.

Another difference between the 4-Digit Code and other guidelines is the use of palpebral fissure length at 2 or more standard deviations below the mean (at or below the 3rd centile) rather than at or below the 10th centile. The facial features used in the 4-Digit Code are evidence based and are linearly correlated with underlying brain damage. These facial features are so specific to FAS that an FAS diagnosis can be made in the absence of knowledge about alcohol exposure. When the criteria are relaxed, however, the facial features are no longer specific to FAS, and rendering a



diagnosis of FAS with unknown alcohol exposure would not be valid. In addition, with relaxed facial criteria, a tool could not be used accurately for screening and surveillance.

Similarly, the 4-Digit Code uses a head circumference threshold at or below the 3rd centile rather than at or below the 10th centile. Head circumference at the 10th centile is within the normal curve, whereas head circumference at or below the 3rd centile is below the normal curve and, in fact, is the medical definition of microcephaly. Most guidelines require only one structural anomaly to serve as an indicator of brain damage for an FAS diagnosis. However, head circumference in the normal range is not a strong predictor of brain dysfunction.

Dr. Astley closed by reviewing key issues for participants to consider. She noted that children should qualify for services on the basis of their impairment rather than on the cause of the impairment.

### **CDC National Task Force on FAS/FAE Diagnostic Guidelines**

**Jacquelyn Bertrand, PhD**, Psychologist, Centers for Disease Control and Prevention

Dr. Bertrand reviewed the CDC's *Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis*. In 2002, Congress mandated that CDC, in collaboration with the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect, develop uniform criteria for diagnosing FAS and other negative birth outcomes related to prenatal alcohol exposure. For 2 years, CDC and the National Task Force, as well as many clinicians, parents, teachers, researchers, representatives of other Federal agencies, and others, examined scientific evidence, clinical expertise, current practices, and information from families to draft the guidelines.

Dr. Bertrand noted that CDC's criteria were developed primarily for medical environments. They were designed to be inclusive and to allow for clinical judgments. These criteria may change over time to address ARND and other disorders.

Because most participants already knew the CDC criteria, Dr. Bertrand focused instead on other topics:

- Considerations for making a differential diagnosis. The guidelines contain information to help clinicians determine whether the presenting abnormalities are the result of alcohol exposure or other causes. Clinicians need to gather a complete and detailed history of the individual and the family to make this determination.
- Guidelines for referral. The guidelines include the following criteria for referral: A child of a mother with confirmed significant prenatal alcohol use should be referred. In addition, a child for whom exposure cannot be confirmed should be referred if the parent or caregiver expresses concern about the child having FAS or if the youth has one of a combination of growth deficits, facial features, and CNS abnormalities.





Dr. Bertrand noted that the document's current focus, FAS, represents only the "tip of the iceberg," as clinical guidelines do not yet exist for partial FAS, ARBD, and various ARNDs. In closing, she added that the various FAS diagnostic tools that are available are more similar than they are different. Further, differences often develop because the tools have unique purposes.

### Questions and Comments

Several attendees commented on their appreciation for this presentation and the work done by panel members to forward the field and give hope to parents. Others expressed their opinions on the inclusiveness of criteria. While one mother cautioned about relaxing the criteria so much that a diagnosis carries less meaning and parents lose hard-earned credibility with the systems they encounter, another participant expressed concern about the criteria being so restrictive that affected children cannot get a diagnosis and are excluded from needed services. When diagnosticians evaluate a child and cannot make an FAS diagnosis, she added, they should note in the medical record, "Although this child does not meet the strict standards for an FAS diagnosis, he or she may still be very disabled from alcohol exposure and needs services."

A mother expressed frustration resulting from the experts' lack of agreement on the criteria. Panel members acknowledged her frustration and added that the criteria can be refined as more data are collected. The process of developing multiple models and challenging them is a standard practice used to move the medical field forward.

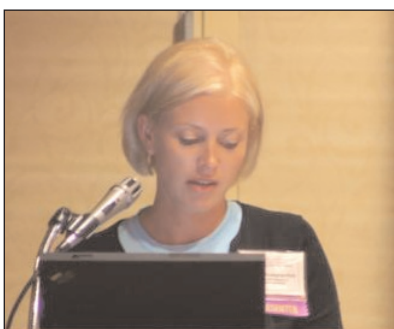
Other comments included the following:

- The guidance from this presentation needs to be translated for Navajo and other audiences that may not understand the science. Many practitioners working with the Navajo Nation do not have access to this information.
- The reauthorization of the Individuals With Disabilities Education Act (IDEA) does not include FAS as a qualifying diagnosis for school systems that are mandated to provide services. Comments are due by July 12.
- Children with FAS commonly receive diagnoses as defined in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), such as conduct disorder, that do not take into consideration underlying neurobehavioral conditions. The interventions designed to address these disorders do not address the real problem.

### Reaching Policy Leaders and Lawmakers

**Moderator: Diane Casto**, Manager, Prevention and Early Intervention Services, Division of Behavioral Health, State of Alaska; Member, SAMHSA FASD Center for Excellence Steering Committee; and Member, National Association of FASD State Coordinators





**Jody Ruskamp-Hatz, MSW**, Policy Specialist, National Conference of State Legislatures (NCSL)

Ms. Ruskamp-Hatz's presentation provided attendees with guidance about how to work effectively with policymakers. She represents the National Conference of State Legislatures, a bipartisan organization that serves the interest of State legislators and provides them with information, materials, and consulting services to help them maximize their effectiveness. NCSL has

issue specialists in all areas, including maternal and child health.

Those working in the field of FASD should get involved with their State legislatures because they control the State's budget and establish programs. However, anyone interested in approaching their policymakers should be aware of the realities of State legislatures, including:

- Term limits and turnover
- Budget cuts and deficits
- Competing demands
- Lack of expertise about specific health issues
- Legislative departments addressing overlapping issues

These challenges create demand for ongoing, consistent education about FASD to ensure that the issue is addressed adequately.

NCSL maintains research on maternal and child health issues and information on State-level activities in these areas. NCSL reviewed State laws related to FAS and found the following:

- 7 States require that warnings be posted in public places.
- 7 States have programs to track FAS or provide research services or direct services.
- 9 States fund prevention and education programs.
- 4 States require reporting incidences of FAS to State health or human services departments or include a diagnosis of FAS as a reason to suspect child abuse or neglect.

Ms. Ruskamp-Hatz highlighted some of the best methods people can use to advocate for the issue of FASD and educate lawmakers. They should maintain relationships with legislators throughout the year, provide written materials and accurate information, personalize the issue, and show how efforts to prevent FASD can save the State money. NCSL has found that concise, easy-to-read graphics can be an effective way to communicate with lawmakers. She shared an NCSL product, a map depicting State-by-State activities related to folic acid awareness, which was printed on a postcard and mailed to legislative staff.



**Kathleen Mitchell, MHS, LCADC**, Vice President and National Spokesperson, National Organization on Fetal Alcohol Syndrome

Ms. Mitchell's presentation focused on the annual NOFAS Hill Day, the Nation's single largest organized FASD advocacy event on Capitol Hill. NOFAS trained people who wanted to participate in Hill Day and arranged meetings with representatives in the Senate and the House of Representatives. This year's Hill Day occurred on May 18, 2005.

Through Hill Day, FASD advocates share their stories with lawmakers, educate them about FASD, and demand their attention to this problem. NOFAS established eight advocacy goals for the 109th Congress, including:

- Reintroduction and passage of the Advancing FASD Prevention and Treatment Act
- Expansion of a program to prevent, identify, and treat FASD in community and Indian health centers nationwide
- Inclusion of additional prevention-based language in and passage of the STOP Underage Drinking Act

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*The energy at the Hill Day  
was upbeat, optimistic,  
and supportive.*

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After detailing the steps NOFAS took in planning Hill Day, Ms. Mitchell shared examples of talking points prepared by NOFAS for people participating in the event. Some directly related to the advocacy goals mentioned earlier. Other talking points urged lawmakers to join the Congressional Caucus on FASD, hold a hearing on FASD highlighting them as a significant mental health/substance abuse or disparity issue, and require professionals regulated by Federal agencies to include FASD-related items on licensing and credentialing exams.

Overall, the energy at Hill Day was upbeat, optimistic, and supportive. More than 50 delegates representing 13 States met with 45 different Senate and House offices. Following Hill Day, delegates sent a thank you letter to the people they met and will plan to meet the Senators and Representatives in their States.

Ms. Mitchell advised participants to use Capwiz, accessible via the NOFAS Web site, to communicate quickly with multiple legislators at one time. The advocacy section of the NOFAS Web site provides more information. She also encouraged participants to get involved in Hill Day. Although policymakers deal with many issues everyday, personal voices are powerful and make a difference.

**Joyce Holl, MAPA**, Executive Director, Minnesota Organization on Fetal Alcohol Syndrome (MOFAS)

Ms. Holl represents MOFAS (the first State affiliate of NOFAS), which became a nonprofit organization in 1998. Its mission is to eliminate birth defects caused by alcohol consumption during pregnancy and to improve the quality of life of individuals and families that are affected.



FASD work in Minnesota started coming together in 1997 when First Lady (and MOFAS founder) Susan Carlson formed the Governor's Task Force on FAS. Subsequently, landmark legislation appropriated \$5 million for prevention and intervention efforts in the State. Due to budget deficits, current State funding is \$1.19 million.

In 2004, the Minnesota Department of Health awarded a 3-year, \$1.19 million contract to MOFAS to coordinate the FASD Statewide Initiative. Through this project, MOFAS aims to develop a statewide presence, maximally involve other systems in the State, and develop a public-private partnership. Ms. Holl remarked on the importance of relationship building in helping MOFAS secure the funding for this project.

Ms. Holl detailed five components of the FASD Statewide Initiative plan and their goals:

- **Diagnosis**—To provide accessible, consistent diagnostic services for individuals who may have an FASD to determine the scope of FASD in the State. As part of this component, MOFAS formed a diagnostic consortium to come to consensus on a standardized protocol with the long-term goal of developing a “Minnesota Model.” The formation of a network of clinics also is part of this component.
- **Intervention and family support**—To enhance the ability of communities, schools, and families to respond to the needs of affected individuals through interventions, support, and training.
- **Public awareness**—To reach youth, women of childbearing age, pregnant women and their families, and the public with messages about prenatal alcohol consumption.
- **Professional education**—To develop a multidisciplinary professional education program for providers who work with individuals with an FASD and their families.
- **Community grants**—To build capacity in communities so they can better leverage their resources, apply culturally competent best practices, and enhance FASD services. Under this component, MOFAS awarded grants to communities. The next grants will be awarded for 5 years, beginning in January 2006.

Other parts of the plan include a transition plan, management and coordination, and research and evaluation.

### Questions and Comments

A few members of the audience reiterated the impact of telling personal stories to legislators. One of them remarked that FASD is not a partisan issue, and another spoke of the financial resources allotted to FASD in Washington State as a result of grassroots family support. Another participant encouraged those interested in advocacy to make a “business case” for FASD efforts by showing that dedicating money to FASD interventions is cost-effective.



## Wednesday, June 22, 2005—Plenary Sessions

### FASD and Behavioral Disorders in Context: Understanding the Behavior of Alcohol-Affected Children

**Introduction:** Carolyn Smith, MSSW, Executive Director, Texas Office for Prevention of Developmental Disabilities; Member, National Association of FASD State Coordinators; and Member, BFSS Planning Committee

**Claire Coles, PhD**, Director, Fetal Alcohol Center, Emory University School of Medicine and the Marcus Institute

Before starting her presentation, Dr. Coles noted that she based the findings in her presentation on published literature and two other sources: The Atlanta Fetal Alcohol Study, a longitudinal study funded from 1980 through 2008, and her work at the FAS Clinic at the Marcus Institute, which has recorded information on 800 children since 1995.

Children with FAS who present clinically share some common problems, including mental retardation, low IQ, learning disabilities, behavioral disorders, poor socialization, and academic failure. However, this general pattern of problems mirrors those seen among children who are referred clinically who do not have FAS and were not prenatally exposed to alcohol.

Dr. Coles explored the question of whether prenatal alcohol exposure has a unique effect on behavior. Although some neurobehavioral outcomes can be attributed reliably to prenatal alcohol exposure, unique effects have not been documented. Research has not identified a distinct pattern of behavior (a phenotype) that can be used for an FASD diagnosis in the absence of knowledge about prenatal alcohol exposure.



The brain and the central nervous system form the basis for all behavior, including cognition, attention, learning, motor skills, language, and emotion. Animals and people exposed prenatally to alcohol experience a range of outcomes, including brain damage, learning disorders, and behavioral disorders, while some demonstrate no evidence of damage. Three important concepts from the science of development shed light on how behavior develops in the presence of various factors:

- Risk accumulation—The effects of layering risk factor upon risk factor to produce a load that impedes appropriate development.
- Developmental psychopathology—The study of how risk factors acting during development may lead to psychopathology (e.g., a behavioral dysfunction, such as attention deficit/hyperactivity disorder, ADHD). Under this multifactor model, behavior does not result directly from exposure. Rather, biologic, familial, social, and other factors work together to affect behavior. Many prenatal factors and postnatal factors affect development.



- “Final common pathway”—A medical term meaning that the number of possible outcomes is limited. Many risks and aberrant developmental processes lead to the same behavioral outcomes. For example, many factors cause ADHD and conduct disorders.

Dr. Coles used the example of arousal dysregulation to demonstrate the complexity of development. According to the literature, arousal dysregulation is probably one of the basic factors that causes later psychopathology. Arousal dysregulation is associated with children who are alcohol and drug exposed, substance abusers who may have some genetic loading for antisocial personality, and family dysfunction. Prenatally exposed children sometimes face all three of these factors and may develop arousal dysregulation that leads to later psychopathology. However, a different set of risk factors, such as preterm birth, maternal depression, and social disadvantage, may result in the same outcome.

Specific cognitive and behavioral outcomes are associated with FAS and FASD, but they are not unique to FAS and FASD. These include the following:

- Cognitive outcomes—Motor problems, visual spatial deficits, cognitive deficits, working memory deficits, and specific academic problems.
- Behavioral outcomes—Arousal dysregulation disorders (e.g., ADHD and conduct disorders), depression and emotional disorders, and socialization problems (e.g., vocational failure, substance use disorders, academic failure).

Dr. Coles focused the remainder of her presentation on the relationship between alcohol exposure and two potential outcomes: arousal dysregulation and delinquency.

**Arousal dysregulation.** An optimal level of arousal exists for various human activities. For example, sleeping requires a low level of arousal, while quiet attention (the optimal level for listening and learning) and active attention (the optimal level for teaching) require a higher level of arousal. Someone with arousal dysregulation cannot maintain the right state to appropriately interact with the environment. A highly aroused baby may not be able to sleep, and a highly aroused child may not be able to pay attention in class.

People who have been exposed to drugs and alcohol have difficulty with arousal regulation. Research indicates that, compared to controls, alcohol-exposed newborns have higher heart rates, infants show more sleep and feeding disorders, and 6-month-olds have problems with information processing. As these children age, they may have difficulty paying attention and may show more aggression and “hyper” behavior. A clear association exists between arousal dysregulation in infancy and preschool and later emotional and behavioral problems. However, this pathway can be modified by environment, and many factors other than drug and alcohol exposure lead to arousal dysregulation, including temperament, brain dysfunction, attachment difficulties, and environmental events.

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*People who have been exposed to drugs and alcohol have difficulty with arousal regulation.*

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People exposed to alcohol have deficits related to attention. Dr. Coles compared the attention deficits associated with FAS to the characteristics of ADHD.

**Delinquency.** Although research has established an association between FAS and delinquent behavior, and many delinquents are alcohol affected, most studies examining this relationship have been conducted with samples of clinically referred or postadjudicated youth. In her research with a nonclinical sample of 14- and 15-year-olds, Dr. Coles determined that a higher instance of delinquent behavior does not exist among the youth who are alcohol exposed compared to youth who are not exposed. Rather, predictors of delinquency were lack of parental supervision, inconsistent discipline, a higher number of negative life events, self-reported substance use, and externalizing behaviors.

In closing, Dr. Coles said that understanding the effects of prenatal exposure on behavior is difficult. We look for simple answers and want to trace behavior directly back to prenatal exposure, but the process is complex and involves confounding and mediating factors. The solutions follow:

- Understand the context and process of development in prenatally exposed individuals.
- Be patient with science. Science provides the mechanism to the solution, but it works slowly.
- While we are waiting for more answers from science, treat the needs of those who are affected.

### Questions and Comments

When asked whether underarousal is a problem in alcohol-exposed children, Dr. Coles said that hyperarousal is more visible and has been better documented. However, data on depression suggest that underarousal also may be a problem, and it needs further examination.

One participant asked Dr. Coles to describe the approaches she uses in an intervention program she referenced during her presentation. The intervention program she is directing is part of a five-site, CDC-funded intervention study. Her site selected math as the core deficit to address. The program includes parent education, a 6-week tutoring program, and guidance to the schools to help them apply developmentally appropriate interventions. Parents learn how to appropriately teach children and help them plan and organize their behavior, and the children learn how to moderate their level of arousal. Preliminary data indicate that most parents are satisfied with the program and that the children are improving as demonstrated on standardized test scores and academic performance.

In response to a question about what concerned citizens could do to attract funders' attention to the issue of FASD, Dr. Coles mentioned several steps she has taken, including asking the legislature for funding; training and educating parents, professionals, and paraprofessionals; and encouraging parents to speak about their experience. The educational effort must be sustained over time to keep the issue in the consciousness of funders.



When asked about the use of medications, Dr. Coles said that many children enter the clinic already on several medications, including antipsychotic drugs. The pattern of inappropriately prescribing drugs begins when children are given sleep medication in their first year. With young children, Dr. Coles said, she would prefer an approach without drugs.

All the participants who asked questions commented on how much they appreciated this presentation and asked that Dr. Coles present again at the next BFSS meeting.

### **FASD Subcontracts: Progress on State Strategic Plans**

**Callie Gass**, Project Director, SAMHSA FASD Center for Excellence

After last year's BFSS meeting, the Center released three requests for proposals (RFPs) open to local communities, States, and juvenile courts. The RFPs called for these entities to integrate FASD prevention or treatment activities into an existing service delivery system following a defined process, including planning for 1 year. Technical review teams scored the proposals, and the Center awarded 35 subcontracts, 10 of which went to States. The number of applications submitted in all three categories far exceeded the number that could be funded.

By integrating an evidence-based practice into an existing service system, the States aim to do one or both of the following:

- Prevent alcohol-exposed pregnancies among women of childbearing age.
- Improve the functioning of those with an FASD to improve their quality of life.

Although the subcontractors plan to address diverse populations, including various ethnic populations in urban and rural settings, they share the same requirements. In the first year, their planning year, each will assemble a task force that includes representation of the target audience, conduct a needs assessment, and develop a strategic plan and an implementation plan to be followed in the next phase beginning in fall 2005. They also are charged with documenting the process, participating in the cross-site evaluation, and ensuring that the change is sustainable.

The Center hopes that the work of the subcontractors will shed light on the process of practice integration, such as whether it can be done, what the barriers are, and how it changes a system. The sites already have learned much about their delivery systems and high-risk populations. For example, the needs assessments revealed the prevalence of guilt, shame, and stigma among the birth mothers of affected children, as well as mistrust among providers of how women report their drinking. These findings will inform the development of approaches. Some findings will also inform the FASD research agenda.

Ms. Gass encouraged participants to talk to representatives of the 10 subcontracted States to network and learn about their activities. In addition, they can visit [www.fasdcenter.com](http://www.fasdcenter.com) to view the resources the Center has made available to the subcontractors.



## Updating State Goals and Objectives

**Jerome Romero**, Principal Investigator, Statewide Fetal Alcohol Syndrome Prevention Project, University of New Mexico; Member, SAMHSA FASD Center for Excellence Steering Committee; and Chair, National Association of FASD State Coordinators

Before explaining the group activity, Mr. Romero briefly described the work of the National Association of FASD State Coordinators, for which he is the Chair. At his request, the NAFSC members introduced themselves so that participants could speak to them later. Mr. Romero noted that members have to be designated by their State (e.g., by the Governor or director of the Department of Health) as the State's focal point for FASD activity.

Mr. Romero has been conducting FASD prevention in New Mexico for the past 8 years. During this time, the State has reduced its FAS incidence rate by half (from 2.2 to 1.1 per 1,000). His advice to the States was:

- Do not be territorial. Agencies and organizations can help each other in various ways, and everyone can play a role in getting the message out that FASD is 100 percent preventable.
- Involve men in FASD efforts. Men want healthy children just as women do.
- Understand that your work is very important—it does not matter what your background is.



Mr. Romero explained the activity, and representatives from each State met to complete a State Team Meeting Worksheet about the State's plans. Center staff provided participants with their 2004 State plans to use as a resource. Items on the worksheet included the following:

- Review the 5-year goals given in 2004 for your State in terms of building a State system to address FASD. Are your goals the same for 2005? If not, what is the new goal? Why has it changed?
- Have you completed the key tasks needed to accomplish your State's goal over the past year? If the goal changed for 2005, what are the key tasks needed to accomplish the new goal?
- List some of the major barriers to achieving your State's goal over the past year. If the goal changed for 2005, what are some of the anticipated barriers to achieving the new goal?
- What are some strategies or steps you have used or could use to overcome these barriers?
- List three action steps toward developing a State system that you would like to accomplish within the next year.



After allowing the States to work for about 20 minutes, Mr. Romero asked two States to present their responses to each of the five questions. Many groups reported that they were pleased with the progress they made in the past year.

Participants gave their State Team Meeting Worksheets to Center staff. Ms. Gass assured attendees that the Center would copy them and mail them to the States after the meeting.

### **Bringing All the Pieces Together: What Does an Ideal System Look Like?**

**Facilitator:** Callie Gass, Project Director, SAMHSA FASD Center for Excellence

At previous BFSS meetings, participants asked about the components of an effective system of care. During this session, participants had the opportunity to deliberate on this question. Participants formed seven working groups to discuss various health and service systems involved in addressing FASD in the States:



- Physical health
- Child welfare, human services, social services, and mental health
- Substance abuse prevention and treatment
- Women's health
- Criminal and juvenile justice
- Vocational rehabilitation/employment
- Native Americans

Each group selected a person to take notes and a person to report the discussion to the larger group at the end of the activity. The Bringing It All Together Worksheet they used during this discussion listed the following items:

- Create a vision. What would the system component look like in an ideal comprehensive system of care?
- State the goals and objectives for this system component in an ideal comprehensive system of care responsive to issues involving FASD.
- What other people, linkages, and resources are needed to make this system component effective in an ideal comprehensive system of care?
- What key elements must be integrated into this component to bring about systems change within a comprehensive system of care?
- List the first steps toward changing this system component in order to build a more comprehensive system of care.



After meeting for about 40 minutes, the seven groups reported on their discussions. Participants gave their Bringing It All Together Worksheets to Center staff. The responses on the worksheets appear verbatim in the attachment at the end of these proceedings.

### **Wrap-Up and Closing Remarks**

**Callie Gass**, Project Director, SAMHSA FASD Center for Excellence

Ms. Gass congratulated Illinois, because last week the Governor decided to convene a task force on FASD. She noted that Illinois was able to accomplish this milestone without a State subcontract from the Center by requesting TA and support from the Center and NOFAS.

Ms. Gass thanked the participants and speakers for attending the conference and sharing with one another. She also reminded everyone to complete and submit their conference evaluation form. After wishing everyone a safe trip home, she adjourned the meeting.

### **Tuesday, June 21, and Wednesday, June 22, 2005—Breakout Sessions**

#### **Addressing Child Welfare and Mental Health Issues for Individuals With an FASD and Their Families**

**Moderator: Michael Dickey**, MPH, CHES, SAMHSA FASD Center for Excellence

**Dan Dubovsky**, MSW, FASD Specialist, SAMHSA FASD Center for Excellence

**Eileen Lally**, EdD, LCSW, Program Manager, University of Alaska, Anchorage

Many individuals and families involved in the child welfare system are affected by substance abuse. The child welfare system comes into contact with a high percentage of individuals, both children and caregivers, with an FASD. Some of those working in the child welfare system lack understanding of the effects of prenatal alcohol exposure and the types of support needed for people with an FASD. As a result, caregivers may be seen as neglectful or noncompliant, and children may end up in multiple foster placements.



#### **Children With an FASD**

An accurate diagnosis of an FASD is the first step toward providing a child with the support he or she needs. A diagnosis can help prepare foster parents, prospective adoptive parents, and case managers for the special needs of the child, thereby reducing disrupted placements and inappropriate treatments. In addition, a child once viewed as noncompliant, uncooperative, resistant, manipulative, and unmotivated (NURMU) may be understood within the context of his or her impairment and environment. Clinicians can assess actual cognitive issues, and caregivers can apply appropriate interventions to help the child thrive.





### **Caregivers With an FASD**

Child welfare social workers aware of FASD will be more able to recognize the possibility of undiagnosed FASD in the child's family members, including his or her caregivers. Several cognitive factors may interfere with a caregiver's ability to respond appropriately to the needs of the child and to navigate the requirements of the child welfare system, including:

- Memory problems
- Language processing problems, especially with verbal language
- Problems with attention
- Inability to process multiple directions
- Literal thinking

In addition, the caregiver may lack support. Rather than assuming that the caregiver is NURMU or neglectful, child welfare workers can recognize that the caregiver may have alcohol-related impairments. In these cases, child welfare workers can use more appropriate approaches, including:

- One-on-one followup with the caregiver
- Regular reminders, for example, about appointment times and rent payment
- Assistance with job coaching to meet the requirements associated with Temporary Assistance for Needy Families (TANF)

### **Mental Health**

A high percentage of people with an FASD have co-occurring mental health disorders. Approximately 50 percent of individuals with a mental illness use substances. Pregnant women with a mental illness, therefore, are at high risk for drinking and having a child with an FASD, and they also may pass on to their child the genetics that placed them at risk for mental illness.

One study examined the mental health disorders among 80 birth mothers of children with an FASD (Astley et al., 2000):

- 96 percent had between 1 and 10 mental health disorders.
- 77 percent had posttraumatic stress disorder.
- 59 percent had a major depressive episode.
- 34 percent had generalized anxiety disorder.
- 22 percent had a manic episode/bipolar disorder.
- 7 percent had schizophrenia.





- 95 percent had been physically or sexually abused.
- 79 percent reported a birth parent with an alcohol problem.

Unfortunately, the various conditions associated with alcohol exposure are not usually identified as co-occurring disorders, because the American Psychiatric Association does not recognize them as mental health disorders. Treatment for an FASD cannot be reimbursed through insurance, and diagnoses based only on symptomatology may be inaccurate. In these cases, the resulting treatments are not helpful.

Common disorders co-occurring with an FASD include ADHD, substance use disorders, and schizophrenia. Likely misdiagnoses include ADHD, conduct disorder, and adolescent depression.

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### Conclusion

To work effectively, treatments should be adapted as needed to accommodate differences in cognitive abilities. Because individuals with an FASD may be very verbal but may have difficulty processing verbal receptive language, those working with alcohol-affected individuals should use simple and literal language. Instructions should be simple and limited to one step at a time when possible. To overcome memory deficits, case workers and mental health providers should provide reminders of appointments or follow a regular routine.

“We must move from viewing the individual as failing if he or she does not do well in a program to viewing the program as not providing what the individual needs in order to succeed” (Dubovsky, 2000).

## Making It Work: Serving the Vocational Needs of Individuals With an FASD

**Moderator: Vicky McKinney**, Co-Director, FAS Family Resource Institute, and Member, SAMHSA FASD Center for Excellence Steering Committee

**Georgiana Wilton, PhD**, Scientist, University of Wisconsin Department of Family Medicine, and Member, BFSS Planning Committee

Dr. Wilton’s presentation focused on the role that work plays in our lives, the types of barriers that individuals with disabilities face in the workplace, and methods employers can use to address these barriers. Solutions to vocational challenges emerged in case studies presented by Dr. Wilton and personal stories shared by an adult with an FASD who has been involved in various vocational settings with different levels of internal and external support. Dr. Wilton stressed the importance of all parties working together to serve the individual. The individual with an FASD needs to be a critical part of the team in discussing the best job and environment for him or herself.



Individuals with disabilities often lack job skills, and they encounter few jobs that best accommodate their needs. Therefore, their placements are often in the food services, hotels, or offices that need administrative help. At work, they face stigma and stereotypes.

Challenges individuals with an FASD face in their working environments include:

- Misunderstanding signals and nonverbal communication, which leads to poor social interaction with coworkers
- Missing deadlines established for tasks, sometimes due to an inability to tell time
- Violating personal space
- Being manipulated by coworkers, who “borrow” money with no intention of paying it back or get them into trouble by asking them to do things that are not appropriate (e.g., “punching in” for someone who is late to work)
- Demonstrating impulsivity and poor decisionmaking
- Being easily distracted
- Dealing with unreliable public transportation, which may cause tardiness

Dr. Wilton provided the following principles for accommodation and intervention in the workplace:

- Least intrusive. The individual should have the level of support in the workplace that he or she requires. However, the situation should provide the greatest amount of independence in which the employee is capable of being successful in the job.
- Natural for the setting.
- In cooperation with the employee. Always involve the employee in making decisions about possible accommodations.
- Start with the environment.
- Build on individual strengths.

### **Discussion**

During the session, Dr. Wilton facilitated discussion, and participants shared their thoughts about these vocational issues. Some of the recommendations they shared are:

- Help individuals develop job skills and a sense of responsibility by having them assist in an elementary school library, office, or other location.
- Visit the work site and conduct an ecological assessment. Most employers would welcome site visits to avoid an inappropriate placement. Dr. Wilton provided a checklist of environmental aspects of job settings that can present barriers to the success of an individual with an FASD.



This list addressed noise, temperature, workstation, accessibility, transportation to worksite, physical requirements of the job, and allergens and hazardous materials. One participant suggested adding restricted areas to the checklist, because an individual with an FASD might not always know that some areas are off limits.

- Be creative in developing new job opportunities and in finding ways to accommodate the individual to ensure success in the workplace. In one example of a creative accommodation, the employee could only manage one task at a time. With the assistance of the job coach, the individual created laminated cards that detailed the daily instructions of his job. With a wipe-off marker, the employee checked each task after completing it. At the end of the day, he wiped the cards clean so that he could use them again.
- Be creative in developing new  
job opportunities and in  
finding ways to accommodate  
the individual.*
- Observe the individual in his or her work environment if a problem develops. A parent or advocate may draw different conclusions from the employee or job coach.
  - Be aware of changes in job responsibilities, job coaches, and work schedules, all of which influence the individual's ability to be successful in the job.
  - Use caution in disclosing information about the disability. Honesty with an employer can be a double-edged sword. While the employer needs to know how to maximize the productivity of the employee, unnecessary stigma should be avoided. The best advice is to ask the individual what he or she is comfortable sharing. In addition, the employee (rather than the job coach) should be the person to disclose information to the employer and coworkers.
  - Address unrealistic expectations. Frequently, individuals with an FASD do not have realistic vocational goals. However, many of the same activities involved in the individual's vocational aspirations can be found in a more realistic job. For example, one girl was interested in becoming a veterinarian. Because she really loved being with animals, her job coach found her a job working at the zoo.
  - Involve the support of an advocate, family member, or friend to help find the best vocational placement for the individual. Because placement agencies benefit financially from placing an individual in a new position every 6 months, their interests may not always be consistent with the needs of the employee. A person with an FASD cannot perform optimally if changing jobs every 6 months. In addition, job coaches may be overwhelmed with cases and may not be able to dedicate adequate attention to one individual.
  - Know and understand the Americans With Disabilities Act (ADA), the law that employers must follow to meet the special needs of individuals with disabilities in the workplace.

A few of the vocational-related resources mentioned during the session include the U.S. Department of Labor Office of Disability Employment Policy (<http://www.dol.gov/odep/>); the Job Accommodation Network (<http://janweb.icdi.wvu.edu/>); the U.S. Office of Personnel



Management (<http://www.opm.gov/disability>); The Arc of the United States (<http://www.thearc.org/>); information on ADA (<http://www.usdoj.gov/crt/ada/adahom1.htm>); and a SAMHSA Publication, *Substance Abuse, Disability and Vocational Rehabilitation*, printed in 1996 and reprinted in 1998.

## Building the Justice System for Children and Adults With an FASD

**Moderator: Catherine Hargrove, MSW, JD**, Technical Assistance Liaison, SAMHSA FASD Center for Excellence

All of this session's speakers were affiliated with one of the juvenile courts under subcontract with the SAMHSA FASD Center for Excellence. Much of this session dealt with these individual projects.



**Susan Carlson, JD**, Juvenile Court Referee/Project Oversight, Hennepin County District Court, Minnesota

Ms. Carlson began her presentation by explaining why States should be concerned about FASD. FASD is a silent crisis, and its societal costs are huge. In addition, FASD is not simply a health issue. For example, children with an FASD become at-risk youth, and many become prison inmates.

Fifty percent of the youth in the Hennepin County detention system have a below average IQ, and 75 percent have family histories of alcohol use. Ms. Carlson addressed the role of the child protective services system, as links exist between child maltreatment and (1) substance abuse, (2) FASD, and (3) juvenile delinquency and criminal behavior.

Ms. Carlson described the work taking place under the juvenile court subcontract and shared some of the program's challenges:

- Getting access to birth mother's prenatal alcohol use/abuse history
- Creating system change in a fragmented system
- Educating service providers
- Removing the stigma associated with a diagnosis of FAS
- Sustaining involvement of the youth and the family in the program after juvenile jurisdiction ends
- Changing how the courts and the whole system handle affected youth
- Sustaining the program after funding ends



The strengths of the program include a history of involvement and support by the State, MOFAS, and the diagnostic clinic.

When asked whether the mothers of youth are being screened for FASD, Ms. Carlson indicated that the process includes an assessment of the families to obtain family history.

**Eileen Bisgard, JD**, Project Director, 17th Judicial District FASD Initiative, Adams County Justice Center, Colorado

Ms. Bisgard described the subcontract under way with the 17th Judicial District FASD Initiative in Adams County, Colorado. This program aims to conduct an FASD screen on every child and youth who comes before the juvenile court because of truancy, delinquency, or child protection concerns. She described how each of these components operates.

Eight school districts in the county participate in the Truancy Reduction Project. In this project, youth who have had a truancy charge filed against them in the system will be screened for FASD, and those who screen positive will be referred for further evaluation. One of the biggest

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*One of the biggest challenges is getting the school system to understand that FASD is a real issue.*

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challenges is getting the school system to understand that FASD is a real issue and to intervene appropriately with alcohol-affected youth. Through the Truancy Reduction Project, Ms. Bisgard hopes to get the school district more involved.

Integrating screening into the delinquency component involves screening the highest risk juvenile delinquent population as it enters probation. Approximately 90 percent of the youths charged with a crime end up on probation.

The Adams County program also will work with children brought before the court due to child protection concerns. Ms. Bisgard noted that 45 percent of the children with mothers who have had dependent child neglect charges filed against them are under the age of 6. In Colorado, children under the age of 6 who are removed from their parent's care must be in a permanent home within 1 year. In addition, in Adams County, hospitals routinely screen for prenatal substance abuse. Positive screens result in removal of the children from the mother's care and placement in the system. The project aims to screen the children. When a diagnosis of an FASD is confirmed, the project will work with the families to teach them how to best intervene with these children.

The Colorado initiative faces many challenges, including getting those involved in social services and mental health and substance abuse treatment to understand how to intervene appropriately with youth who have an FASD. In addition, many of the children have had multiple placements in the dependency system.



**Kathryn Kelly**, Project Director, FAS/FAE Legal Issues Resource Center, Fetal Alcohol and Drug Unit, University of Washington

Ms. Kelly first outlined the findings from Ann Streissguth's 1996 secondary disabilities study and explained how these findings pertain to the justice system. She also described her subcontract. The King County juvenile justice system will work with all clients who enter drug court or a mental health center. They will begin by adding some questions to the initial jail interview to form a prescreen. Those with a positive score on the prescreen will be referred to Ms. Kelly and a social worker for further screening and, if necessary, referral to a diagnostic evaluation. If an FASD diagnosis is obtained, they will identify resources and work to modify programs for the individual to increase the client's opportunity for success. The program will include working groups of professionals to help modify drug treatment, mental health treatment, and sexual deviancy treatment as needed.

One of the barriers faced by this program is the perception of probation officers that the youth are "problem kids" rather than alcohol affected. In addition, parents have not been made part of this process.

One of the participants asked whether confidentiality regulations limited the court's access to records. While the courts can order the records, access is variable.

In response to questions about the costs of screening, presenters indicated that their subcontracts with the SAMHSA FASD Center for Excellence absorb these costs. However, sustainability is the goal, as subcontract funding is finite.

### **The Importance of Addressing Physical Health Issues for Individuals With an FASD**

**Moderator: Pamela Gillen, RN, ND, CAC II**, Project Coordinator, University of Colorado Health Sciences Center; Member, SAMHSA FASD Center for Excellence Steering Committee; and Member, National Association of FASD State Coordinators

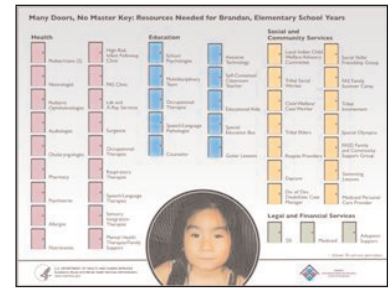
**Julie Gelo**, Parent and Family Advocate/Trainer, University of Washington Fetal Alcohol Syndrome Diagnostic and Prevention Network, and Member, SAMHSA FASD Center for Excellence Steering Committee

Ms. Gelo, the parent of 13 children, adopted Brandan when he was a baby. When he was born, he faced many medical problems related to his prenatal history and birth. His birth involved a host of complications, including breech delivery, meconium aspiration, and respiratory distress. He was discharged from the hospital at 10 days, weighing 4 pounds 7 ounces. Long-term medical concerns included microcephaly, chronic respiratory difficulties, feeding difficulties, growth deficiencies, global delays, congenital syphilis, and FAS. Although Brandan exhibits all the characteristic features of FAS, the degree to which FAS contributed to Brandan's various medical problems is unknown. Ms. Gelo's presentation detailed the physical challenges Brandan experienced at various stages throughout his life:





- 3 months—Brandan manifested many respiratory and feeding difficulties, and he had a cleft palate. At age 3 months, he saw a neurologist, and at 3 months and 2 weeks, he received a diagnosis of FAS.
- 6 months—In spite of getting a gastrostomy tube, or G-tube, Brandan stayed below the first percentile for weight.
- 12 months—Brandan required a high level of medical intervention and had three appointments with doctors per day. He received care from many therapists, including a speech pathologist. Even with physical therapy twice per week, Brandan could not crawl. During this time, Brandan participated in a tribal naming ceremony and was given the name Red Hawk. For the first time, Ms. Gelo believed Brandan would survive.
- 24 months—Brandan walked with an orthopedic walker.
- 30 months—Brandan walked on his own.
- Elementary school years—Brandan's needs have changed. The diagram "Many Doors, No Master Key" shows how many special services were needed for Brandan. ("Many Doors, No Master Key" slides depicting Brandan's needs at age 1 to 2 years and during the elementary school years are available on the SAMHSA FASD Center for Excellence Web site.)



Today, Brandan still has feeding and sleeping difficulty, and he requires a special classroom and help in places such as the cafeteria and playground.

Brandan's birth mother agreed to terminate her parental rights and died 3 months later. Three years to the day afterward, his father died. In addition, Brandan's grandparents died in their 30s. All these relatives died from the results of alcoholism.

Many factors place a child at risk for prenatal alcohol exposure and FAS. The prenatal risk factors in Brandan's history included:

- Daily alcohol exposure
- Minimal prenatal care
- Poor nutrition
- Homelessness
- Domestic violence
- Exposure to syphilis

However, many factors in Brandan's life also serve as protective factors, encouraging him to grow and thrive. These include his innate resiliency; his early diagnosis and intervention; excellent medical care; consistent involvement of social services; access to ongoing interventions and

resources; and the safe, stable, and nurturing home in which he lives. Brandan was diagnosed early by a multidisciplinary diagnostic team that was invaluable in recognizing his many needs and recommending appropriate therapies and resources.

**Luther Robinson, Jr., MD**, Associate Professor of Pediatrics, Children's Hospital of Buffalo

The term "fetal alcohol spectrum disorders" describes the breadth of growth, structural, developmental, and social deficiencies experienced by individuals prenatally exposed to the human teratogen ethyl alcohol. The domains for diagnosis include prenatal exposure to alcohol, growth deficiency, central nervous system dysfunction, and craniofacial dysplasia.

The pathogenesis of FAS is not fully known at the molecular level. Possible mechanisms include interference with the action of growth factors, induction of excess free radical formation, excessive cell death (apoptosis) via cell adhesion molecule pathways, alcohol enzyme polymorphism, effects on neural crest cell migration, and effects on *Shh* expression. *Shh* is a gene that is depressed by alcohol in African Americans.

FAS is a specific pattern of birth defects caused by prenatal exposure to alcohol. It is a medical diagnosis. Several different sets of criteria have been developed to diagnose FAS. The criteria developed by the Institute of Medicine in 1996 address history of maternal alcohol use, growth deficiency, characteristic facial manifestations, and central nervous system abnormalities.

When presented with a medical problem, the medical model aims to "find it and fix it." Questions asked under the medical model include:

- What is the chief complaint?
- What is the history?
- What are the physical findings?
- What is the diagnosis or differential diagnosis (list of possibilities organized by priorities)?
- What is needed to confirm or refute the diagnosis?
- What is the treatment plan?



FAS causes many developmental delays. However, not every child with a developmental disability has FAS. Many other conditions demonstrate similar characteristics to FAS, including Williams syndrome, velocardiofacial syndrome, DeLange syndrome, Dubowitz syndrome, and childhood mental illness. Diagnosticians need to rule out these other conditions before making a diagnosis of FAS.

When parents learn that their child has been diagnosed with FAS, their responses may include a feeling of loss of an expected outcome, anger, denial, and acceptance. Over time, these feelings may reoccur unexpectedly.



Manifestations of FASD vary with each individual from infancy to adulthood. Each developmental stage poses different challenges that require different methods of responding. For instance, in infancy, a child may need early intervention programs and swaddling, whereas a toddler may need speech therapy, occupational therapy, and help transitioning into the educational system. In primary school, neuropsychological testing and behavior modification may be necessary. Further educational supports may be needed in the middle school years.

In adults, life skills training may be an appropriate intervention. In addition, FASD is often accompanied by secondary disabilities, such as mental health problems, disrupted school experience, and trouble with the law. Intervention strategies and services must be available, accessible, and acceptable.

### **Sharing the Real Story: Native American Children and Their Families Dealing With the Challenges of Living With an FASD**

**Moderator: Louise Ashkie**, Program and Project Specialist, Fetal Alcohol Syndrome Project, Navajo Nation; Member, SAMHSA FASD Center for Excellence Steering Committee; Member, National Association of FASD State Coordinators; and Member, BFSS Planning Committee

**Larry Foster**, Parent of an Individual With an FASD, Navajo Nation

Mr. Foster and his wife adopted Ricky on October 2, 1987, through the American Indian Child Welfare Act. The Act allows Native families to adopt Native children before they become available for adoption by families of other ethnic groups. According to hospital medical records, Ricky was born on April 6, 1985, in an alley in Gallup, New Mexico, to an alcoholic Navajo mother who had received no prenatal care. When he was brought to the hospital by emergency medical personnel, he smelled of alcohol. Ricky experienced alcohol withdrawal with seizures 8 hours after he was born. His heart stopped, and medical staff had to revive him.

Through research, the Fosters found that Ricky was part of the Tsa'naa'Bilt naa' (Sleep Rock Clan) and Riyaa'anni (Towering House Clan). The Towering House Clan is the first clan of the Navajo people. Ricky graduated from Gallup High School with a special education certificate and was baptized in both the Native American church and Christian church. His parents have taught him culture, spirituality, and religion, which has helped him to grow and heal. Ricky's Indian name is Two Stars.

Ricky was evaluated by a team of physicians at Gallup Indian Medical Center/IHS in 1987 and was diagnosed with FAS. The family faced many challenges in obtaining services for him. The school system, including the staff, was not familiar with FASD. The family had to become knowledgeable about special education laws in order to advocate effectively. Services were not readily available for Ricky, and his teachers did not understand his behaviors, such as his inability to understand



social cues. They also did not understand what he needed to succeed, such as a consistent structure and a focus on positive behaviors.

Ricky's parents enrolled him in activities such as swimming and t-ball to help him grow and develop outside of school. His teenage years brought additional challenges, including inappropriate behaviors that resulted in his becoming involved with the juvenile justice system. His family provided strong boundaries and interventions to keep him out of the justice system.

As Ricky transitioned into young adulthood, difficulties with service systems continued. The services available have not always met his needs. His family continues to provide positive reinforcement and encourages Ricky to participate in religious and spiritual activities. Ricky was accepted into a State job training program. He now has his own vehicle and delivers newspapers. He recently secured his own apartment and would like to take some life skills courses at a community college.

**Cynthia D. Beckett, PhD, RNC**, Director of Professional Practice and Research, Flagstaff Medical Center

**Louise Ashkie**, Program and Project Specialist, Fetal Alcohol Syndrome Project, Navajo Nation; Member, SAMHSA FASD Center for Excellence Steering Committee; Member, National Association of FASD State Coordinators; and Member, BFSS Planning Committee

Dr. Beckett conducted the study Navajo Children and Families Living With Fetal Alcohol Syndrome (FAS)/Fetal Alcohol Effects (FAE) in Navajo Nation to develop a culturally sensitive grounded theory of Navajo parenting for families who are living with FASD. She worked through all required tribal entities to receive the necessary permissions to conduct the research. The goal was to identify the social and cultural factors and processes Navajo families use to manage care for a child with an FASD. Dr. Beckett selected grounded theory for the study because of the social processes found within the population. Navajo is a culture of storytelling, cultural rituals, and ceremonies. When she was exploring the culture, Dr. Beckett found that the traditional beliefs, practices, and values appeared to be linked to social processes.

The informants were members of 13 Navajo families raising a child or children with an FASD. The interviews were conducted within the homes with the mothers, and two interviews were conducted with adolescents. To be included in the project, an informant had to be registered as a Navajo and be the primary caregiver of a school-aged child with an FASD. Family members also were needed to demonstrate the ability to cope with the difficulties of parenting children with an FASD.

The philosophical perspectives that guided the study were the Navajo view of life, resilience, family stress theory and the resiliency model of family stress, and adjustment and adaptation. A literature review was conducted to frame the study.



A grounded theory of Navajo parenting emerged from the data. The core category identified was “versatility through transcendence.” Within this core category, Dr. Beckett identified four major components:

- Strategies for managing challenges—In managing challenges, the women had developed coping skills through their strengths. The women used the limited resources available to them. There was an intergenerational integration of traditional and contemporary knowledge, beliefs, and practices that included a kinship connectedness to their clan. The women used affection and nurturing, maintained harmony and balance (mind-body-spirit), and applied the knowledge and skills that they had acquired.
- Intergenerational substance abuse, suffering, and violence—The cycle of domestic violence and alcohol abuse crossed generations. Often, alcohol was a way to self-medicate to deal with the suffering. The women used resources and incredible strengths to cope with this.
- Transcendence in parenting—In parenting, the women had to deal with the various challenges involved with raising a child with an FASD. Those who had more information had more success in parenting.
- Knowledge/acquisition of services—In some areas, women needed access to more information. Women who had information were better able to access services and felt better equipped to handle their various issues. The women wanted culturally appropriate parenting services. The provision of services and transportation was critical.

Factors that influenced the women’s resilience, adjustment, and adaptation in parenting will be disseminated to health care providers, counselors, teachers, and community members to assist Navajo families who are managing the problems associated with FASD. This knowledge will improve the effectiveness of referrals for the child and family and, ultimately, improve outcomes.

Further data collection is needed to continue exploration in areas such as affection and nurturing, transcendence over challenges, application of knowledge and skills, and secondary mental health problems. Dr. Beckett is working to access funds to continue this study in other regions of the Navajo Nation to test and further develop the theory of resilience, adjustment, and adaptation for Navajo parenting.

### **Circle of Hope: Addressing and Preventing FASD in Addiction Treatment**

**Moderator: Sandra Van Campen, MS**, Perinatal Substance Abuse Prevention Consultant, Montana Department of Public Health and Human Services

**Diane Malbin, MSW**, Executive Director, FASCETS, Inc.

Ms. Malbin began her presentation with a definition of a “social problem.” She stated that a social problem becomes an issue when it affects a significant number of people or a number of significant people for which there is a solution.



Ms. Malbin referenced a research study that was conducted in Canada to locate information on FAS interventions. An extensive literature review on FASD identified 16,913 references, but these included only 10 articles on intervention studies that met the established criteria. Researchers located and reviewed seven of them. Of these, two were medication trials, one was a cognitive control study, one was a supplementary reading program, one addressed functional analysis, and one was a multisystems collaborative community-based intervention study.

This exercise made clear that the interventions used to address the neurobehavioral disorders of those with an FASD applied models based on learning theory as the dominant paradigm. Ms. Malbin questioned whether learning theory and behavioral techniques recognize the implications of neurocognitive disorders. She compared learning theory–based assumptions and FASD characteristics (see the table below).

Learning Theory–Based Assumptions	FASD Characteristics
Process quickly	Slower processing speed
Store, integrate information	Problems storing and linking information
Abstract	Concrete, experiential
Generalize	Difficulty retrieving, applying
Predict	In the now, problems abstracting
“Age appropriate”	Developmental dysmaturity

Ms. Malbin’s Canadian Project hypothesized that because FASD is a brain-based disorder with behavioral symptoms, techniques based on learning theory would not be effective in addressing FASD. Rather, by taking into account the characteristics and symptoms of FASD when designing interventions, one could significantly reduce secondary behaviors in children. This approach also would reduce stress and increase a sense of personal competency among the adults who care for children with an FASD.

Ms. Malbin also explained that fetal alcohol spectrum disorders have been underrecognized by the social service and medical fields because practitioners feel that no solution has been identified to address them. She explained that drinking is a reality and an issue for people in all disciplines and all systems. Denial of the problem translates into compromised systems of care.

Ms. Malbin argued that solutions may be found by reexamining the way we provide services to individuals with an FASD. With solutions comes the opportunity for all disciplines to recognize and address issues of FASD and to develop a multisystem continuum of care. She identified addiction treatment as a key place to begin developing a comprehensive system, starting with providing information to women in treatment and supporting sobriety to prevent relapse. Programs also need to address the special needs of women in treatment who have an FASD.





Systems solutions presented by Ms. Malbin included:

- Recognize the personal/professional dynamic.
- Establish a safe “no shame/no blame” context.
- Recognize the limits of current techniques.
- Create a common cross-discipline language shared among parents and professionals.
- Recognize the need for time “infusion” of information.

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*Solutions may be found by  
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**Kathleen Mitchell, MHS, LCADC**, Vice President and National Spokesperson, National Organization on Fetal Alcohol Syndrome

Ms. Mitchell told her story of being the birth mother of a wonderful child, Karli, who was born with FAS. She then spoke of the importance of examining relapse among women in treatment. Women who used alcohol during pregnancy have severe guilt and shame that needs to be addressed in order to prevent relapse. Women who have children with an unidentified FASD are also at high risk for relapse because of the behaviors of their children and their belief that they are poor parents. Women in treatment who have an FASD may be at increased risk as well.

FASD prevention and intervention are priorities in addiction treatment. Women who are addicted to alcohol are at very high risk for having a child with an FASD, and women who drank during one pregnancy are likely to drink during other pregnancies. In addition, early identification of children with an FASD can reduce secondary disabilities and improve outcomes.

Several efforts are under way to teach women in treatment and treatment professionals about FASD. These include infusing FASD information into the curricula used by addiction professionals, convening women in recovery summits, developing Circles of Hope, and showing in treatment settings the *Recovering Hope* video produced by SAMHSA.

Ms. Mitchell discussed the myth that an addict will not enter treatment until she has “hit bottom.” In reality, an addict lives in an emotional bottom. The top three barriers to addiction treatment for women are the inability to admit that the problem is severe enough to warrant treatment, the lack of emotional support for treatment from family members, and the inability to provide adequate care for children. Ms. Mitchell reviewed some of the past and current models of addiction, including the disease model.

Women who are addicted have lost their voice and turned off their inner wisdom. They often have low self-esteem, feelings of powerlessness, and a history of abusive relationships. The most beneficial treatment for these women provides comprehensive services, including food, clothing, shelter, transportation, employment, legal assistance, educational opportunities, child care, and social services. In addition to addressing the women’s basic needs, programs should add a feminine focus when appropriate.



Individual counseling and group sessions should address issues around sexuality, gender, menstruation, physical abuse, substance use during pregnancy, and the women's desires and dreams. Because women may be especially vulnerable to relapse during periods of hormonal change, programs also should help women anticipate changes associated with menstruation and menopause. This process prepares the women for hormonal fluctuations and teaches them alternative methods of coping rather than taking drugs.

Ms. Mitchell also addressed the need to identify clients who may have an FASD themselves. She listed the items that need to be included in an intake assessment to gather information about potential alcohol exposure. Clients with an FASD require modified treatment approaches. Suggestions included:

- Limiting cognitive assignments
- Eliminating lecture-style treatment and allowing the client to stand or leave the room if needed
- Assigning buddies
- Allowing the client to discuss her disorder in small groups
- Helping the client to accept the degree of the disability

When working with alcohol-affected women, counselors should expect and be prepared for:

- Inconsistent behaviors
- Problems with perception, decisionmaking, and attending to time
- Impulsive behavior
- Frustration with transitions
- Need for additional one-on-one sessions

Ms. Mitchell also detailed the types of treatment services women might need while in residential treatment and aftercare. Counselors need to know that women with an FASD can learn with repetition and support, and the system of care must be adapted to fit the client's needs.

### **FASD Prevention: Implementing Project CHOICES**

**Moderator: Felisha Dickey, MSW, MPA**, Social Work Consultant, Florida Department of Health, and Member, National Association of FASD State Coordinators

**Kirk von Sternberg, PhD**, Senior Research Associate, University of Texas Medical School at Houston

The Centers for Disease Control and Prevention conducted a study called Project CHOICES (Changing High-Risk Alcohol Use and Increasing Contraception Effectiveness Study) in 1997 when evidence emerged that alcohol consumption could damage a fetus early in pregnancy.





The basis of Project CHOICES is a preconception intervention to prevent the spectrum of disorders that result from prenatal alcohol use. Women who are drinking at risk levels (determined by NIAAA) and are not contracepting effectively are at risk of having an alcohol-exposed pregnancy. This intervention is based primarily on constructs of the transtheoretical model. Project CHOICES was designed to address alcohol use and contraception use among high-risk women. Changing either behavior (or both) results in no risk for an alcohol-exposed pregnancy.

Dr. von Sternberg's presentation described the work of three CDC grantees that implemented Project CHOICES trials. Some of the steps taken could be adapted and implemented by other organizations.

### **Epidemiological Study**

The epidemiological study conducted at the three sites focused on identifying high-risk populations. Researchers assessed the risk of women in jail, recovery centers, gynecological clinics, health centers, and other locations. Although all the settings had a higher proportion of women at high risk for an alcohol-exposed pregnancy than the estimated average rate for women age 18 to 45 years, researchers identified women in the treatment center and jail as being at the highest risk. All these settings represented ideal locales for designing and testing interventions to reduce the rate of alcohol-exposed pregnancy. Risk for alcohol-exposed pregnancy was associated with several factors, most notably current drug use and current smoking.

### **Feasibility Study**

Essentially a pilot study, the feasibility study aimed to design an intervention and determine how feasible it was: Would it be accepted by the women? Could women in high-risk settings be recruited? Could interventions be developed that would target both behaviors that place women at risk? Since there was no control group, this study was looking for the promise of effectiveness.

The project spent a year developing the intervention and manuals, training therapists how to apply motivational interviewing techniques, and developing the assessment package. During this study, 190 women participated in the treatment condition—a 6-week intervention—and 3- and 6-month followups. Dr. von Sternberg described the components of the intervention, including attention to the women's readiness to change. During the 6-week period, women in the study attended four sessions and made one gynecological visit. Dr. von Sternberg noted that fewer sessions may be just as effective, as indicated in new research findings.



Components of each session of the project were:

- Session #1—Orient the woman to the study, obtain informed consent, build rapport, conduct assessment, provide fact sheets, provide a “gift pack” (including project materials, condoms, resources, and other materials), make an appointment for a gynecological exam, and assign homework about self-monitoring and the good and “not so good” things associated with drinking and changing drinking (decisional balance).
- Session #2—Address personalized risk using forms, provide feedback, review self-monitoring log and homework, gauge readiness for change using the self-evaluation ruler and address readiness, and set initial goals.
- Gynecological visit—Conduct a history, provide contraception education and counseling, conduct an exam if desired by the woman, and provide contraception. Project staff made the appointment for the women and then followed up afterward to ensure that the visit occurred. The project used Planned Parenthood providers.
- Session #3—Review the self-monitoring homework; debrief on the doctor’s visit; and revisit the readiness rulers, decisional balance, and goals statement.
- Session #4—Review prior sessions, develop a final goals statement and change plan for alcohol and contraception use, discuss current decisional balance, discuss self-efficacy, schedule followup, and provide a certificate of completion.

The timeline follow-back method, developed by Mark and Linda Sobell, was used to maintain a daily record of alcohol use and contraceptive activity.

While all the women in the study were at risk prior to the intervention, 68.2 percent were not at risk at the 6-month followup. More women chose to effectively use contraception than to reduce their drinking, although about half the successful women did both.

### **Efficacy Study**

During the feasibility study, the model demonstrated sufficient promise to warrant a randomized control trial, or an efficacy study. In this phase, 827 women from the same three cooperating State sites were randomly assigned to one of two conditions (treatment or information only). The results of the efficacy study will be published soon.



## Attachment Notes From Bringing It All Together Worksheets

### System Component: Physical Health

- 1. Create a vision. What would the system component look like in an ideal comprehensive system of care?**
  - Care manager to coordinate various service providers alongside the parent/caregiver
  - Interdisciplinary focus
  - Touchpoints model
  - Medical home or service coordinator models
  - Integrate children diagnosed with FAS among those with other disabilities
- 2. State the goals and objectives for this system component in an ideal comprehensive system of care responsive to issues involving FASD.**
  - Diagnosis
  - Intervention/treatment
  - Support/facilitation for parents
  - Enhancing transitions as child gets older, common language
  - Maximize/optimize outcomes for child
  - FASD screening for child, parents, and siblings
- 3. What other people, linkages, and resources are needed to make this system component effective in an ideal comprehensive system of care?**
  - Need someone to help caregiver navigate through the system
  - Extend it to residential system
  - Parent sponsor
  - Funding
  - Mechanism for sharing information among parents
  - Electronic passport



**4. What key elements must be integrated into this component to bring about systems change within a comprehensive system of care?**

- Funding
- Insurance company/managed care support
- Education, mental retardation/developmental disability, medical/health—needs to be seamless
- Diagnostic clinic

**5. List the first steps toward changing this system component in order to build a more comprehensive system of care.**

- Mandatory education of service providers in a multidisciplinary team. This includes substance abuse, FASD, intervention/treatment, medical, nursing, occupational therapy, physical therapy, speech, and educators.
- Building diagnostic capacity
- Identify specific responsibilities to service providers
- Data, evidence to support efficiency/efficacy of system
- Eliminate turf issues
- Birth registries—get a handle on how many cases exist

**System Component: Child Welfare, Human Services, Social Services, and Mental Health**

**1. Create a vision. What would the system component look like in an ideal comprehensive system of care?**

- Children at the top of the family list. One-stop shop—a child would be assigned to a case manager who has been specially trained in FASD to connect and take the child to service systems that have a common understanding of FASD.

**2. State the goals and objectives for this system component in an ideal comprehensive system of care responsive to issues involving FASD.**

- Global assessment to follow child
- Money will follow the child
- Have FASD as a primary component of diagnosis (Axis I, not III)
- Massive FASD education of community
- FASD screening for child, parents, and siblings





**3. What other people, linkages, and resources are needed to make this system component effective in an ideal comprehensive system of care?**

- Licensure component on FASD for professionals: doctors, therapists, social workers, etc.
- Services—parent advocate, respite, substance abuse screening, education
- Get FASD education on agenda at agency meetings and trainings
- Not just mention FASD, but describe what FASD looks like and how it affects neurobehavior
- What key elements must be integrated into this component to bring about systems change within a comprehensive system of care?
- Standards for minimum care management in family-centered, strengths-based practice
- Support systems for case managers
- Family choice of case managers and services
- Manageable caseloads

**4. List the first steps toward changing this system component in order to build a more comprehensive system of care.**

- Training—comprehensive for all domains
- Substance abuse screening at all points of entry
- Referral to case manager at point of positive FASD screen
- Designate or identify the parent advocate: birth mother, husband, grandparent, etc.
- Obtain funding provided by a nationwide tax on alcohol and have it be at a location such as Department of Maternal and Child Health as opposed to DHHR, etc.

**System Component: Substance Abuse Prevention and Treatment**

**1. Create a vision. What would the system component look like in an ideal comprehensive system of care?**

- Addictions treatment would be involved in a seamless continuum of care where all in the community are equally well trained to participate in an informed and appropriate system of care that understands the implications of FASD and women's issues.

**2. State the goals and objectives for this system component in an ideal comprehensive system of care responsive to issues involving FASD.**

- All mandated trainings include relevant and appropriate curriculum on brain dysfunction associated with alcohol and addiction in proportion to the need



- Educate licensure boards (national/CRC)
- Get FASD included in certification
- Add language and certification requirements to the local, State, and national contracts, RFPs, and exams
- Increase capacity of rehabilitation facilities for women in treatment with children and specifically incorporate the implications of FASD as a physical disability in programs
- All programs should be reevaluated annually for their appropriateness for neurocognitive disorders

**3. What other people, linkages, and resources are needed to make this system component effective in an ideal comprehensive system of care?**

- Trained child care workers in FASD
- All women and children entering treatment should be screened and evaluated for neurocognitive disorders
- All systems of care screen and evaluate clients for neurocognitive disorders
- Multidisciplinary collaborations
- Federal agencies (CDC, NIAAA, etc.) need to collaborate

**4. What key elements must be integrated into this component to bring about systems change within a comprehensive system of care?**

- Substance abuse treatment centers partner with children and family agencies/cross-trainings to prevent failure and enhance outcomes

**5. List the first steps toward changing this system component in order to build a more comprehensive system of care.**

- Educate, apply, evaluate, reeducate
- Train all pediatricians, OB/GYNs, and others in health care, criminal justice, and early intervention in FASD
- Create options for treatment that include an extended treatment model that provides training in the recovery community to support transition into the community
- Family systems treatment based on the Swedish model



## System Component: Women's Health Addressing FASD

- 1. Create a vision. What would the system component look like in an ideal comprehensive system of care?**
  - A comprehensive, integrated, and developmentally and culturally appropriate system of care that women can readily access throughout the lifespan
- 2. State the goals and objectives for this system component in an ideal comprehensive system of care responsive to issues involving FASD.**

### Goals

- Prevention and education
- Identification and diagnosis
- Treatment
- Evaluation and data-driven quality improvement
- Surveillance of in utero alcohol exposure

### Objective

- Increase societal knowledge of the harmful effects of alcohol consumption before, during, and after pregnancy
- 3. What other people, linkages, and resources are needed to make this system component effective in an ideal comprehensive system of care?**
    - Adequate funding
    - Political will
    - Champion in higher levels of government
    - Appointment of a State coordinator
    - Convene steering/advisory group of key stakeholders
    - Advocacy by affected families
  - 4. What key elements must be integrated into this component to bring about systems change within a comprehensive system of care?**
    - Strong data component
    - Evidence-based practice
    - Three Cs: communication, commitment, and coordination



- Training of all service providers
- Legislative support

**5. List the first steps toward changing this system component in order to build a more comprehensive system of care.**

- Create a State/national priority with a focus on alcohol prevention before, during, and after pregnancy
- Create a steering committee (key leadership among stakeholders)
- Implement an FASD planning process (needs assessment, strategic plan, implementation, and evaluation)

**System Component: Criminal and Juvenile Justice (Focusing on Juveniles)**

**1. Create a vision. What would the system component look like in an ideal comprehensive system of care?**

- A comprehensive system of care with voluntary FASD screening and diagnosis in diversion programs and screening of adjudicated juveniles (delinquents, truants, and runaways)
- Referral for diagnosis, services, and treatment for this population with transition services to adulthood

**2. State the goals and objectives for this system component in an ideal comprehensive system of care responsive to issues involving FASD.**

**Goals**

- Reduce recidivism
- Increase compliance with probation
- Improve family and school functioning

**Objectives**

- Tailor current interventions to enhance family functioning, with families (primary caregivers) participating in planning, as well as the juvenile
- Have in-home services available
- Planning should be strengths-based and support resiliency
- Tailor school services so that schools are active partners participating in the wraparound process



- Services to be provided in a wraparound model, including unpaid services such as mentoring
  - Preparing youth for transition should include peer education
- 3. What other people, linkages, and resources are needed to make this system component effective in an ideal comprehensive system of care?**
- The Governor, legislature, Congress, and key State and county positions should be adequately informed and prepared to move forward
  - Families with individuals affected with an FASD or developmental disabilities and advocates to work with policymakers in an umbrella partnership
- 4. What key elements must be integrated into this component to bring about systems change within a comprehensive system of care?**
- HCBS waiver or other funding available to support and sustain services
  - Single point of entry
  - Education at all levels in the juvenile justice system and of all parties involved
  - The system created should apply to abused and neglected children
  - “Delinquents under age 10” program
- 5. List the first steps toward changing this system component in order to build a more comprehensive system of care.**
- Form umbrella group or task force that also addresses prevention of secondary disabilities
  - Conduct a needs assessment
  - Get buy-in, including funding support, for the system

### **System Component: Vocational Rehabilitation/Employment**

- 1. Create a vision. What would the system component look like in an ideal comprehensive system of care?**
- Mutually beneficial employment for persons with an FASD at a livable wage
- 2. State the goals and objectives for this system component in an ideal comprehensive system of care responsive to issues involving FASD.**

#### **Goal**

- Mutually beneficial employment for persons with an FASD at a livable wage



## **Objectives**

- Reliable, affordable, safe transportation
- Educated workforce (employers, tax credits)
- Educated service providers
- Consistent, appropriate job coaching
- Supportive income, “financial safety net”
- Transition planning
- Educational planning, vocational skills incorporated at all levels
- Early diagnosis and treatment
- Self-advocacy training and support
- Person-centered, family-centered planning
- Strengths-based “building a platform for success”

### **3. What other people, linkages, and resources are needed to make this system component effective in an ideal comprehensive system of care?**

- Government financial agencies: Social Security, Medicaid waiver/Medicaid
- Government service agencies: Department of Vocational Rehabilitation, Justice, Child Protective Services
- Schools/education
- Employers
- Universities, training centers
- Legal advocacy

### **4. What key elements must be integrated into this component to bring about systems change within a comprehensive system of care?**

- Buy-in from all other components
- Education of other systems
- Awareness and understanding
- Accountability, watchdog





**5. List the first steps toward changing this system component in order to build a more comprehensive system of care.**

- Add vocational issues to existing national FASD committees (ICCFAS, FAS Task Force)
- Add FASD training to existing agencies for individuals with developmental disabilities
- Maintain a focus on vocational issues at future BFSS meetings

**System Component: Native Americans**

**1. Create a vision. What would the system component look like in an ideal comprehensive system of care?**

- Comprehensive, community-based system of care developed by each tribe
- Cultural and spiritual sensitivity
- A system that includes individuals, families, clans, and tribal communities
- Access to a full range of services

**2. State the goals and objectives for this system component in an ideal comprehensive system of care responsive to issues involving FASD.**

- Involve Indian Health Service at BFSS meetings
- Include Native Hawaiians in RFP
- Use culturally competent methods to engage Native tribes in collaboration

**3. What other people, linkages, and resources are needed to make this system component effective in an ideal comprehensive system of care?**

- IHS
- Funding
- States

**4. What key elements must be integrated into this component to bring about systems change within a comprehensive system of care?**

- State support
- Accurate studies
- Data needed
- Diagnostic clinic



**5. List the first steps toward changing this system component in order to build a more comprehensive system of care.**

- Sovereign nations/direct CHS/needs assessment
- Each tribe has different needs and resources (depends on size, location, and whether or not the tribe is recognized by the Federal Government)
- Need for data (screening); the “one size fits all” approach does not work
- If children are screened, they need followup
- Need for resources and capacity building
- Eliminate shame and stigma when identifying children
- States do not know how to access or work with tribes; this needs to be corrected

**Other Issues for Native Americans**

- Each tribe is different
- Some tribes are dry, while some tribes have casinos and alcohol is available
- Some tribes get no State support
- IHS not keeping accurate statistics on birth; studies and data are needed
- Omaha Tribe—funded by FAS study; prevention side more acceptable in Omaha
- Stigma attached to identifying a child with FAS
- Rural areas do not have women-focused treatment
- Each tribe has its own individual history and circumstances
- Navajo Nation—has services but is not interested in dealing with FASD
- Within a reservation—people off reservation not eligible for some services; community-based efforts are more flexible
- Artificial boundaries
- Many young mothers
- Some families have five generations of alcoholism
- Shame and guilt
- Peer educators
- No funding for FASD or a lot of funding for FASD

